

AUTISM SOCIETY
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Illinois



AUTISM AWARENESS



HOPE

POSSIBILITIES

OPTIONS

EDUCATION AND TRAINING

Marklund expands services for children on autism spectrum

BY JANICE YOUNGWITH

Reading, writing and arithmetic aren't the only challenges faced by today's school-age children.

Academic, social, behavioral and life challenges are multiplied when the child has been diagnosed with a physical, emotional or developmental disability such as autism.

"I became an educator because I wanted to help

children overcome their limitations," says Karen Gill, director of education at Marklund, an organization serving children and adults with profound disabilities.

As a child, Gill was physically impaired with a prognosis of becoming non-ambulatory if she didn't undergo a medical procedure.

"The procedure was a success," recalls Gill, who coordinates curriculum and



DANIEL WHITE / dwhite@dailyherald.com

Marklund is a nonprofit organization that serves more than 200 children and adults with severe and profound developmental disabilities at its Bloomingdale and Geneva campuses.

special educational services for children ages 3 to 22 at the Marklund Day School in Bloomingdale. "I was even able to compete in two NCAA Division I sport teams and overcome my limitation.

I feel so fortunate to be part of an organization that makes everyday life possible for students with profound disabilities."

Gill's efforts and those of her highly trained colleagues at Marklund will expand as the school itself expands with a \$4 million state-of-the-art building program that focuses specifically on children on the autism spectrum.

Thanks in large part to a \$3.5 million donation bestowed on Marklund by the Ann Haskins Foundation, the school will expand its life skills program, which provides specialized education and training to students ages 3 to 22 who have been diagnosed with an autism spectrum disorder.

The new 12,000-square-foot, two-story building will be built adjacent to the current school building at 164 S. Prairie Ave. Features of the new Ann Haskins Center will include seven classrooms, therapy rooms, a multipurpose room, offices and observation areas.

Construction is expected to begin this spring, with doors of the new center opening to students in January 2015. A capital campaign to support the project is being implemented by the organization.

"It is good news indeed to learn of the expansion of local services, intensive programming and options for parents and families," says Mary Kay



Marklund was founded by Stanley and Claire Haverkamp in 1954.

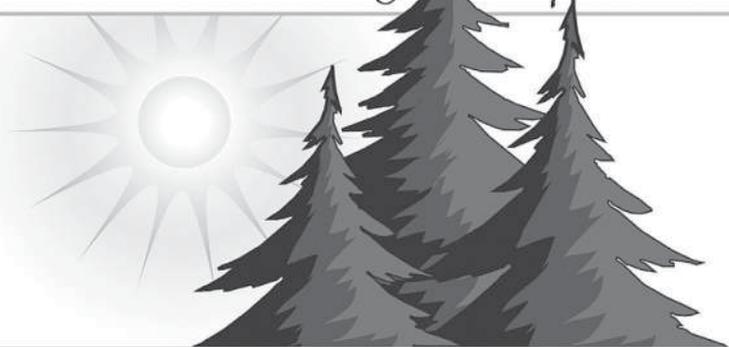
Betz, executive director of the Autism Society of Illinois, who notes that both nationally and on the local front, the growing number of children with autism is astronomical, and the impact for families and society epidemic.

GRANT EXPANDS LIFE SKILLS PROGRAM

According to Gilbert Fonger, president and CEO of Marklund, the grant allows for expansion of the school's life skills program for students on the autism spectrum. The state-of-the-art facility will be built from the ground up with the needs of children with autism in mind, according to Marklund officials.

Continued on page 4

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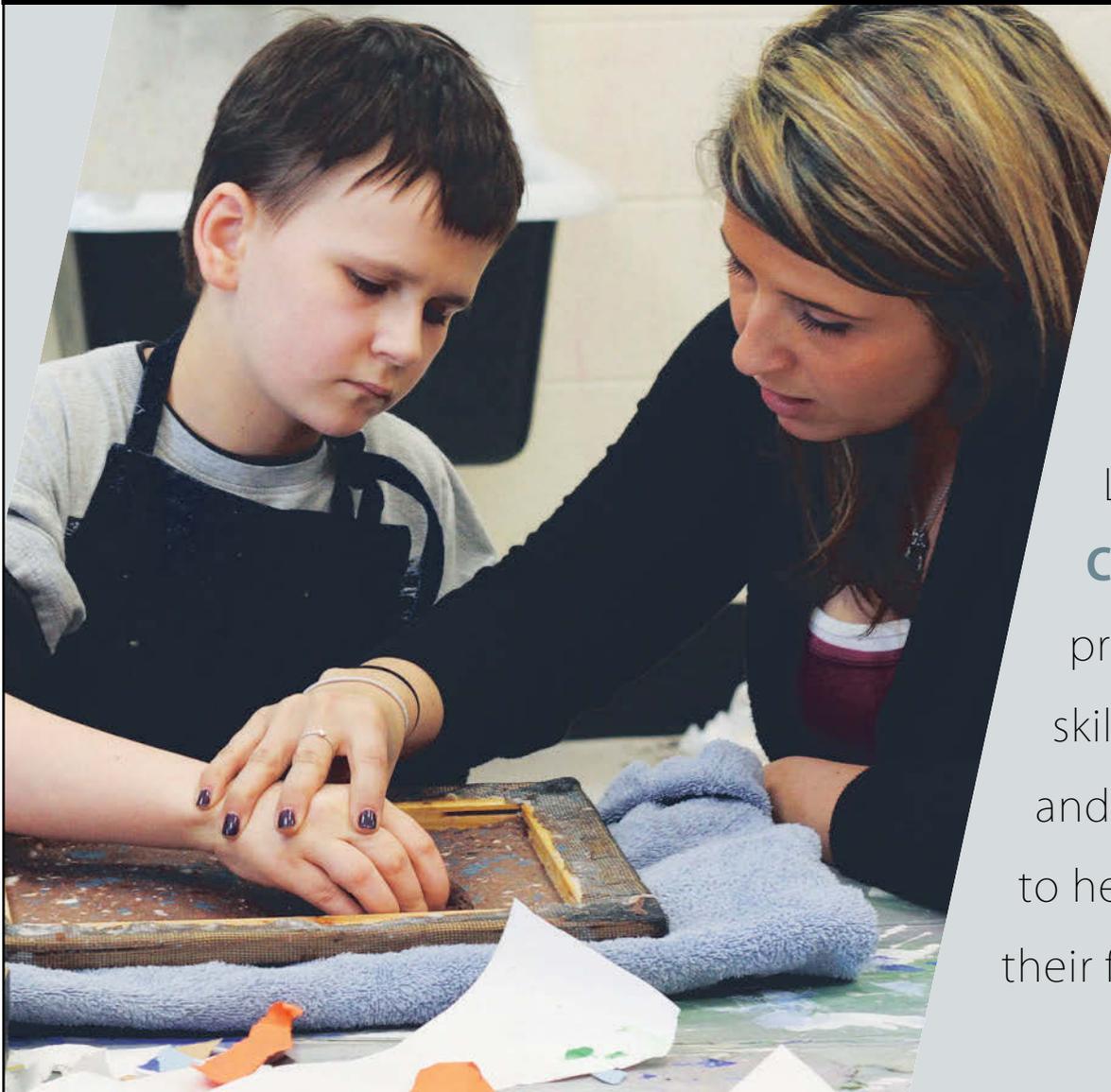
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Continued from page 2

The school's life skills program began in 2010 as an extension of the day school to serve those children specifically on the autism spectrum. Space constraints in the Marklund Philip Center for Children, which houses the school, has limited the number of students able to be served. With the planned expansion, the school should be able to increase its enrollment by an additional 50 students and 40 new staff members.

"We are so pleased to be able to serve more students who need our specialized program," says Gill. "We currently partner with 23 public school districts to give them a place to send those students whose needs cannot be met at their own school."

According to Gill, students may need to be transported to the Marklund Day School for any of a variety of reasons, ranging from space or financial limitations to inability to manage the severity of the student's disabilities.

"Special education directors at our partner districts are looking forward to our expansion and being able to observe best-practice techniques in the hope that they may be able to duplicate teaching methods back at their own campuses. It is always our goal to eventually be able to transition the students back into their home districts."



Marklund is building a \$4 million state-of-the-art expansion, set to open in January 2015, at its Bloomingdale campus.

The planned observation windows will allow district administrators, teachers, student teachers and parents to observe activities in the classrooms without being intrusive in the class and being noticed by the students.

"Everything from lighting and designated safe zones to transition spaces and classrooms are planned to enhance and optimize the educational experience," she explains. "Everything from the height of every window, curvature of the walls and placement of benches in the hallways will be determined

with the assistance of an autism consultant."

She says that because autism is extremely unique, the lab school program is highly individualized with curriculum designed around each individual student. In addition, specific therapies and built-in supports, such as an occupational therapy sensory room, snoezelen-controlled multisensory environment and different behavior outlets, all are planned as part of the program.

"We provide year-round educational program with consistent therapy service," explains Gill, who notes that the life skills program provides additional combined therapy minutes to students' documented minutes of service to support individual student achievement.

PARTNERING TO ENHANCE TRAINING

The foundation and its trust, which were established in 1986 for Ann Haskins of St. Charles by her mother, Mary, to commemorate Ann's life and support other young people with disabilities "by providing the highest quality special education for children in DuPage and Kane counties," also granted a similar amount to Wheaton College.

The college, according to the Ann Haskins Foundation, will use the donation to create



a special education program to give college students pursuing a degree in education the opportunity to receive training in special education methods. Marklund and Wheaton College have formed a partnership through the Foundation to share information and give college students the opportunity to observe and obtain clinical training at the expanded Marklund Day School.

A HISTORICAL PERSPECTIVE

Marklund was created in 1954 when a nurse by the name of Claire Haverkamp began providing foster care to an infant named Mark William Lund, who was born with Down syndrome and severe cardiac issues. The organization grew as the Haverkamps continued to care for more children

with developmental and physical disabilities. They built the current Marklund facility on Prairie Avenue in Bloomingdale in 1957. The Marklund Day School was established in 1979 to serve children like those cared for at Marklund — medically fragile children with multi-needs, including serious developmental and physical impairments, and who, because of their profound disabilities, cannot have their educational needs met at public schools.

Founded in 1954, Marklund is a nonprofit organization that serves more than 200 children and adults with severe and profound developmental disabilities at its Bloomingdale and Geneva campuses. Both locations provide residential, therapeutic and educational services, as well as developmental training. For more information, visit www.marklund.org.

What is autism?

According to the Autism Society of America, autism spectrum disorder is a developmental disability considered the result of a neurological condition affecting normal brain function, development and social interactions. Children or adults with autism often find it difficult or impossible to relate to others in a meaningful way and may show restrictive patterns of behavior or body movements.

Leading developmental experts point to autism as a complex developmental disability that typically appears during the first three years of life and affects a person's ability to communicate and interact with others.

Children on the autism spectrum develop a neurological architecture, which creates a black-and-white way of thinking and processing information. Because of this, they often may develop rituals or routines or suffer in areas like social interaction and communication.

Parents seeking support, additional information and resources relating to autism spectrum disorders should contact the Autism Society of Illinois at 2200 S. Main St., Suite 203, Lombard, call (630) 691-1270 or email betzm@autismillinois.org.

About Autism Society of Illinois

Autism Society of Illinois (ASI), the Illinois affiliate of the Autism Society of America (ASA), is ranked in the top 10 of all ASA Chapters nationally, based on the quality and level of support offered statewide.

Its mission is to partner with families and communities living with autism in Illinois by generating awareness and providing education, training, support and guidance as a compassionate and caring authority.

ASI's vision is communities that understand, accept and support families and individuals living with autism.

The affiliate works to improve the lives of individuals and families in Illinois affected by autism spectrum disorders.

To ASI, "people affected" includes: individuals with autism, their families, teachers, physicians, therapists, bus drivers, restaurant owners, etc. It does this by providing individualized information and support referrals to individuals who are affected by autism today.

ASI understands that autism is a lifelong disability. It is here to provide support and advocacy and to increase awareness and acceptance throughout the state.

The Autism Society of Illinois programs include:

- Special education advocacy.
- Specialized training to parents, first responders, and school districts.
- One-on-one assistance for families and individuals in real time.
- Increasing public awareness of autism.
- Referral network of hundreds of services and programs across the state of Illinois.

- Legislative support at the local, state, and federal levels.
- Family outreach.

For more information about the Autism Society of Illinois programs and events please contact Libby Wojda at Libby@autismillinois.org or (888) 691-1270.

Visit www.autismillinois.org or call (630) 691-1270 for additional information or to make a donation.

ASI Staff

Executive Director:
Mary Kay Betz, Kane County

Information and Referral Coordinator: Libby Wojda, DuPage County

IEP Specialist: Ron Lampon, Cook County

Accountant: Lisa Grywza, DuPage County

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SCHOOL FOR PROFESSIONAL STUDIES

DIVERSITY AND INCLUSION

Hanover Park resident succeeds at OfficeMax

BY JANICE YOUNGWITH

Like many young adults, Josh Enda of Hanover Park says he dreamed of finding the perfect job — one with a good salary, where he could succeed and overcome challenges, and one that would offer a steady paycheck despite the tough economy. Thanks to a little support from job coaches and a local West suburban human services agency helping those with disabilities, the 28-year-old man who has autism and lives at home with his family, says he is on the road to success.

THE CHALLENGE

Like many with autism spectrum disorders, Enda faced a daunting set of obstacles in an already difficult job market. Understanding assignments, getting along with co-workers, learning terminology, demystifying nonverbal cues and unraveling workplace social cues could be particularly challenging.

“Without supports, job prospects for adults with autism in the U.S. are bleak, with an employment situation owing much to the basic nature of autism spectrum disorders,” says Mary Kay Betz, executive director of Autism Society of Illinois. “The growing numbers of children and adults living with autism is astronomical, and the impact for families and society huge. Developmental disability also can impair communication skills, speech, fine motor skills and behavior.”

With a one in every 50 children receiving an autism

diagnosis, it is anticipated that this year more than 500,000 young people with these disorders also will turn 18 with hopes of entering the workforce.

Leading experts indicate that autism spectrum disorders are a complex developmental disability that typically appears during the first three years of life and affects a person’s ability to communicate and interact with others. It is defined by a certain set of behaviors and is a spectrum disorder that affects individuals differently and to varying degrees.

Many children on the autism spectrum develop a neurological architecture that creates a black-and-white way of thinking and processing information. Because of this, they often suffer in areas like social interaction and communication. They also may develop many rituals and routines.

WORKING FOR SOLUTIONS

Now working as one of the 130 distribution associates at the 350,000-square-foot OfficeMax Distribution Center in Itasca, Enda is among those finding success thanks to a new national inclusion and diversity program offered by his employer. According to Marcia Gordon, vice president of career and life enrichment for Aspire of Illinois, a local human services agency that began partnering with OfficeMax three years ago, the partnership is opening doors to success for a number of individuals with autism and other disabilities.



Thanks to a little support from job coaches at Aspire of Illinois, 28-year-old Josh Enda is on the road to success at the OfficeMax Distribution Center in Itasca.

“Together we took a close look at bolstering the job interview and application process, redefining interview techniques and wording, developing specific job coaching and offering workplace specific pre-employment job prep,” she explains.

Due to their partnership with OfficeMax, the agency designed a special off-site replica of the retailer’s distribution center and a retail store, enabling those in the pre-training process to get a hands-on feel of actual operations and learn techniques, processes and work flow.

“There’s no job guarantee, but many of our clients are finding the program can open doors to careers they never dreamed possible,” says Gordon, who notes that Aspire of Illinois is in talks with other local companies also interested in diversifying their workforce and hiring those with developmental and physical disabilities.

“When given the opportunity, those with disabilities have the determination and skills to greatly contribute to an organization,” she says and adds that employee dedication and productivity improves, increasing the bottom line.

Enda is one of Aspire of Illinois’ shining success stories, according to Lisa Dziergas, director of community employment services

for Aspire of Illinois, who works closely with clients, job coaches and employers.

“It is our goal to prepare clients to find rewarding employment in the community, supporting each individual in finding and maintaining a job that best fits their strengths and interests,” she says.

With Angelica Cardoso, a job coach from Aspire of Illinois, providing one-to-one on-site assistance at his workplace, Enda was quick to learn and understand new job demands.

“Now working a standard eight-hour shift and mandatory overtime during prime retail sales months, his work is judged for accuracy and production rates,” Cardoso explains. “Within two weeks of initial training, he was hired and on his way to becoming independent. Josh is quick to understand, has a firm grasp of necessary math skills and pays great attention to detail.”

While initial job coaching focused on work processes, Enda also received help recognizing nonverbal cues from his supervisor and co-workers.

“Natural workplace supports have now taken over, and very little job coaching assistance is needed,” explains Cardoso, who notes that independence is the ultimate goal.

For Josh Enda, who has been on the job for more than

a year, the satisfaction of a job well done comes from tracking his production rates of at least 95 percent and maintaining accuracy percentages.

“Math is something I understand and can relate to,” he says. “It’s what I do best.”

MAXING OUT DIVERSITY

Aspire of Illinois is among the first in the nation to participate in “Maxing Out Diversity,” a grant-funded employment project of the Kessler Foundation. The foundation recently awarded a \$323,333 signature employment grant to the Association of People Supporting Employment First (APSE) to work with OfficeMax to develop a model of successful employment for people with disabilities. More than \$2.17 million in grants money was distributed this year by Kessler Foundation to improve employment and job training options for Americans with disabilities.

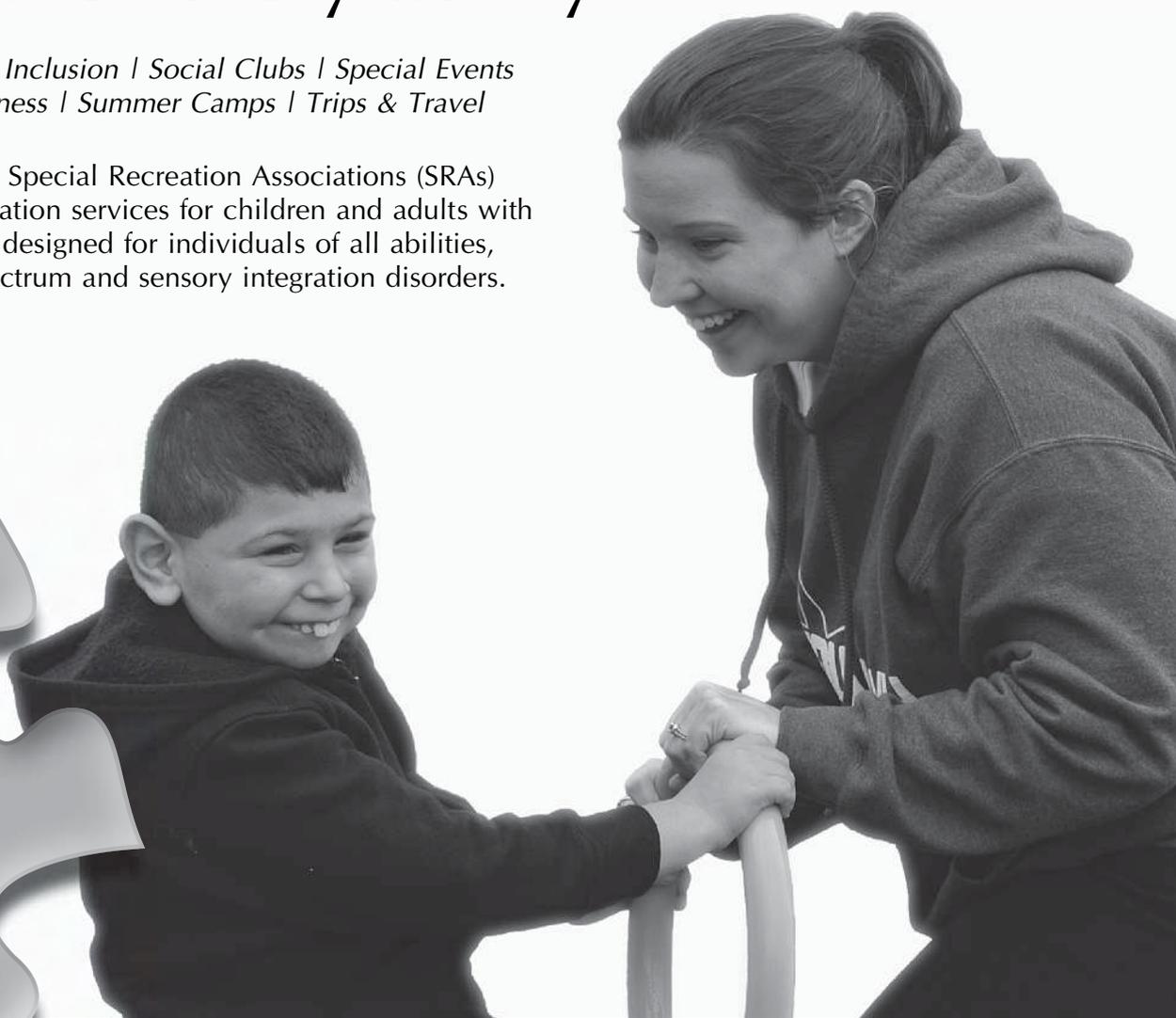
The goal of the OfficeMax program is to nurture the careers of trainees toward success in their professional careers. Utilizing the spider concept, specific training centers, including Aspire of Illinois in Westchester, initially support a distribution center, eventually “spidering” out to area stores.

Continued on page 12

Special Recreation Associations— A perfect fit for every ability.

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Northern Suburban Special
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nssra.org



NWSRA
Northwest Special
Recreation Association
P (847) 392-2848
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SEASPAR
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WDSRA
Western DuPage Special
Recreation Association
P (630) 681-0962
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FINANCIAL PLANNING

Special needs trust, guardianship key issues for parents

BY JANICE YOUNGWITH

Parents of children on the autism spectrum aren't alone in their concerns about the future, according to Thomas Clark, an estate planning law attorney and the father of a 10-year-old son with autism. Clark says one of the most challenging issues facing parents of children with special needs is planning for their child's future without them.

"Careful planning is necessary to preserve eligibility for most publicly funded disability related programs, especially as the child reaches the age of majority — usually 18 years of age," says Clark, who notes sooner rather than later is the general rule of thumb when it comes to beginning the planning process.

"Maintaining eligibility for basic government programs, for which they are rightfully entitled, is important," says

Clark, who notes other concerns such as guardianship, powers of attorney and more also need to be considered in the comprehensive and individualized planning process.

"As well, the family should understand that government benefits like Medicaid, Medicare, SSI and SSDI likely will not meet all the child's needs."

Parents or guardians of a dependent with special needs, like autism, often come to a point when they realize their son or daughter may need extra help throughout their lifetime, according to Clark, who notes that the early teen years are a prime time for this realization to occur. As the father of a pre-teen son, Jack, who has autism, Clark knows the value of planning for the future.

"Many parents are likely to be familiar with the legal document commonly known



Jack Clark's future is secure because his parents prepared a special needs trust for him.

as the special needs trust," says Clark, who adds that with the help of an attorney who has expertise in this area, parents are able to create a special needs trust to provide extra and supplemental care, maintenance support and education above and beyond that which is already provided by any local, state and federal programs.

"With a special needs trust in place, families are taking a giant step toward securing a future of financial security for their loved one with special needs," he says. "Once a special needs trust is established, the most important step

involves funding it. Parents may leave a portion or all of their estate to the trust; inheritances from relatives or friends can be gifted to the trust; and investments such as CDs, IRAs and Keogh plans and life insurance can also be directed to the trust."

Clark, whose estate planning law practice today is focused on helping families navigate and document financial, educational, personal care and health decisions, cautions that legal terminology and phrases commonly used in estate planning can be confusing.

"Whether you are worth \$50,000 or \$5 million, you need to consider who will make important decisions on your behalf in the event you are unable to make these decisions," he says. "For parents with special needs children, it is especially important to have a plan in place."

Clark says guardianship can be an especially tricky decision. "Many parents simply aren't certain of the need for guardianship, and it's a highly personal consideration," he says.

"Guardianship, which is a common concern at age 18, essentially takes away the legal rights of an individual and is a serious matter. However, if the child is seriously disabled and will not be able to make decisions for himself, it is vital."

For those not certain, Clark advises testing and working with a physician or psychologist to determine the extent of a disability. He also says using documents such as the "durable power of attorney" for finance, health care and education can work until such time as needs are better known.

"I sometimes refer to this as guardianship light," says Clark, who notes that the durable powers of attorney documents are more flexible and still leave some decisions to the young adult.

"It's never too late to start planning for the future," says Clark, who admits it's not surprising that most parents or guardians of dependents with special needs are challenged to find the time to focus on their own needs or those of the rest of the family.

"By working with an experienced financial and legal professional, you can make an important difference in how you map out a future of financial security for your entire family, including your loved one with special needs."

Parents seeking support, additional information and resources relating to autism spectrum disorders should contact the Autism Society of Illinois at 2200 S. Main St., Suite 203, Lombard, call (630) 691-1270 or e-mail betzm@autismillinois.org.

Special needs trusts

While there are many types of trusts, two are especially important for parents whose children have special needs.

The supplemental discretionary special needs trust is designated to receive inheritance from life insurance policies upon the passing of a parent, grandparent or another specially designated family member. These "third party" special needs trusts give parents the ability to leave money for the benefit of their child without affecting public benefits the child may receive.

Funding may come from contributions or inheritances and may be received from anyone but the disabled child. Parents typically act as trustees, and later, a designated trustee can be named to handle trust distributions for things like a residence, car, medications and therapy, education, travel, entertainment, electronics, clothing and other living expenses.

A Medicaid payback trust, sometimes referred to as an OBRA trust, is used for assets deemed to be resources of the child. These trusts commonly are used for child support payments, lawsuit settlements and inheritances the child receives in their own name, rather than specially designated for a discretionary supplemental trust.

This type of a "payback" trust can safeguard money and prevent the government from taking trust assets into account when determining government benefits. Whatever assets remain at the termination of the trust revert to the government agency providing the assistance.

ASI calendar of events

► *Autism Society of Illinois Casino Night — Raise the Stakes and Bring Awareness to Autism*

When: Friday, Feb. 21, 7-11 p.m.

Where: 100 Drury Lane, Oakbrook Terrace.

Tickets: \$150 per person.

For details: Email libby@autismillinois.org or call (888) 691-1270.

Join us for a night of drinks, food and Las Vegas-style entertainment. Casino Night winnings may be traded in for tickets for more than 30 amazing raffles prizes. The night will include:

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► *Chords for Kids*

When: Saturday, March 8, at 7 p.m.

Where: Wentz Concert Hall at the Fine Arts Center, North Central College, 171 E. Chicago Ave., Naperville.

Eighth annual free concert for children with autism and their families. Music and motion come together as children with autism and other special needs enjoy performances of classical music in a world-class concert hall. Admission is free, but tickets are required; call the North Central College Box Office at (630) 637-SHOW (7469).

► *The Autism Society of Illinois 10th Annual Parent and Professional Networking Conference*

When: Saturday, March 15.

Where: La Grange Highlands Middle School, 1850 W. Plainfield Road, La Grange.

Contact: The Autism Society of Illinois at (630) 691-1270 or email libby@autismillinois.org.

Twenty speakers, five tracks — adults, biomedical, behavioral, advanced and advocacy. This networking conference will help you gain information to assist in your quest to make a difference in your own life or in the lives of those with autism whom you love, teach and support.

► *Jump for Autism Awareness Day — Skydive Chicago*

When: Saturday, April 26, 9 a.m.-6 p.m. (Rain date: Sunday, April 27)

Where: Skydive Chicago, 3215 E. 1969th Road, Ottawa.

Reservations/information: Visit Skydive Chicago at skydivechicago.com to reserve your tandem jump online or call (815) 433-0000. Be sure to mention your reservation is for the Jump for Autism Day.

Cost for jumps the day of the event: \$200 per Tandem Jump (\$50 from each jump will be donated to ASI)

A percentage of proceeds will be donated to the Autism Society of Illinois. Festivities include a bake sale and raffle drawing. Join us that evening in the Sky Lounge Restaurant for dinner, drinks, DJ and for the announcement on how much we raised.

► *Change for Autism Fundraiser 2014*

When: April 1-May 15

Schools across the state will raise awareness and funds to help support families who are touched by autism. All money raised in Illinois stays in Illinois.

Contact the Autism Society of Illinois to let us know that your school or district will be joining our efforts. Pick a week that your school or district will be collecting change. We will give you the directions once you contact us.

The school that raises the most money will receive two iPads for its special education department. The top class from each school will get a choice of party. For more information, email libby@autismillinois.org or call (888) 691-1270

► *For a full list of events visit www.autismillinois.org.*

What about guardianship?

When a child attains 18 years of age, the laws of Illinois presume that child is capable of making both personal and financial decisions.

“Consequently, parental authority to make decisions regarding a child’s education, medical care and living arrangements expire when the child becomes an adult at 18,” explains Thomas Clark, an estate planning law attorney who frequently speaks to parents of children with special needs at Autism Society of Illinois events. “Should you believe it is in your child’s best interest for you to continue making personal and/or financial decisions on behalf of your child, you must be appointed as their guardian.”

Steps required to become guardian of your child:

Step 1: File a guardianship petition. To serve as guardian, individuals must be 18, a United States resident and not be a convicted felon.

Step 2: Set a date. Clark recommends working with a legal adviser to set a date for the guardianship hearing. “Pick a date when you and preferably your child are able to attend,” he recommends. “If your child cannot attend this hearing, or if the judge believes the guardianship hearing will be too stressful for the child, the court will appoint a guardian ad litem. The guardian ad litem’s role is to represent the interests of your child and to be the court’s eyes and ears.”

Step 3: Obtain a doctor’s report. The doctor’s report is a two-page form that is completed by a medical doctor (M.D.) and is the main piece of evidence the court uses to determine the extent to which a child can make personal or financial decisions and whether guardianship is required.

Step 4: Send official notification. Arrange for official notification of all interested parties once the hearing is scheduled. You must notify interested parties of the date, time and location of the hearing. Parties include your child, the child’s other parent and adult siblings. This notice requires that your child be served a summons to appear in court.

Step 5: Attend the guardianship hearing. At this hearing, the judge will interview you and any other interested parties present, ask questions about your child’s daily needs and your plans for the child. If present, the judge may also ask your child questions or they may ask the guardian ad litem. They will read their report into the record. If all goes well, you will be appointed legal guardian.

Step 6: Receive legal notice. Within a few weeks of the hearing, you will receive a Letters of Office notice confirming your authority to make decisions in behalf of the child.

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CHILDHOOD DEVELOPMENT

Navigating milestones when your child has a developmental disability

By JANICE YOUNGWITH

Navigating the physical, developmental and social milestones of childhood can be tough, especially for parents who have a child with a developmental disability like an autism spectrum disorder.

Those families face a host of additional challenges, including untangling the complex web of government benefits, rules and regulations, says Sherri Schneider of Family Benefit Solutions in Buffalo Grove, a consulting firm that specializes in helping families apply for and obtain Social Security and Medicaid benefits. "It can be a confusing and daunting process."

Schneider, who is a popular guest speaker at gatherings of parents whose children all have special needs, frequently refers to the government's "house of benefits" and its inherent rules for entering each specially designated "room" for Social Security, Social Security Disability Insurance, Medicaid and Medicare benefits.

"It's important to understand requirements for each 'room' and to know what steps are necessary to determine eligibility," she says. "These rules vary depending upon age and other factors."

As one example, she says if you are over the age of 18, not married, have a disability that began before the age of 22, are receiving SSI and one of your parents receives Social Security benefits for retirement, disability or is deceased, the Social Security Administration will consider you a disabled adult child.

"If you qualify as a disabled adult child, you will be eligible to receive monthly payments through the Social Security Disability Insurance program (SSDI)," says Schneider. "Even

though you must be over the age of 18 to qualify, the SSA will consider you a disabled adult "child" because you will be collecting SSDI based on your qualifying parent's Social Security earnings."

She adds that if you are receiving SSDI as a disabled adult child and you get married, in most situations, you will not be able to receive SSDI benefits any more. However, if you get married to another disabled adult child, you may still be able to receive SSDI benefits.

Finding additional supportive state-funded services for those with autism and other developmental disabilities begins by contacting one of several local coordination agencies that act as the "front door" to Illinois' state-funded service system.

Schneider and other experts say following a timeline can help avoid pitfalls and point parents in the right direction to find government funding and help.

AS SOON AS POSSIBLE

Develop a special needs estate plan. Include wills, special needs trust(s), powers of attorney and change of beneficiary. Use an attorney whose practice is limited to these issues and who keeps up with the ever-changing rules.

BIRTH TO AGE 3

Have your child evaluated for your state's early intervention programs. To locate the Child and Family Connections office for your area, call (217) 782-1981.

Do not open any assets in your child's name. "Let others know this as well," cautions Schneider, who says unexpected financial windfalls and gifts can jeopardize future

benefits for your child.

"In addition, you'll want to work with a qualified financial planner to begin planning for your financial health in terms of retirement, disability benefits, life benefits and to help creatively fund a special needs trust for your child."

Ask about receiving a comprehensive diagnostic evaluation and/or speak with your pediatrician regarding concerns.

"To be eligible for the state's early intervention program, a child must demonstrate a 30 percent delay in at least one area of their development," explains Andrea Sagel, occupational therapist and autism services coordinator at Easter Seals DuPage and the Fox Valley Region, an accredited outpatient pediatric rehabilitation center in Villa Park.

"Some children can benefit from therapy services even if their developmental delay is less than 30 percent."

Ensure continuity and coordination of care. It's important to follow through on other concerns, says Sagel.

"The first five years are critical in a child's life, and this is the most important time to get your child support for a developmental delay or special need." As kids age, she says, it is vital to ensure continuity and coordination of care by sharing evaluations, diagnostic and progress reports with medical and therapy teams, as well as with the educational team.

AGE 3

Seek school district support and services. A school advocate or attorney may be of assistance in identifying and receiving the services your child needs.

Register for PUNS. If your child has the diagnosis of

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SSA/Security
Disability Income

Medicare

Supplemental
Security Income

Medicaid

Consultant Sherri Schneider helps parents understand the government's "house of benefits" and its inherent rules for entering each specially designated "room" for Social Security, Social Security Disability Insurance, Medicaid and Medicare benefits.

a developmental disability or an autism spectrum disorder, register on Illinois' Prioritization of Urgency of Need for Services (PUNS) database.

This important state registry functions as a database and waiting list for services. Call your Independent Service Coordination Agency (ISC) at (800) 588-7002 or (888) DDPLANS. You may request funding for services such as respite, the children's waiver, a home-based services waiver, job coaches and group homes.

Educate Yourself. Attend as many conferences as possible to obtain information for your child's future. Check out school presentations or visit The ARC of Illinois online at www.thearcofil.org for a listing many presentations.

Support from fellow parents is available from the Illinois Statewide Advisory Council on Developmental Disabilities online at www.iacdd.org. Area wide work groups also are a good source of information and support.

AGE 14½

Begin transition planning. At school, ensure your child's individualized education plan

reflects realistic goals and future planning for work, living arrangements and more.

AGE 18

- Apply for SSI benefits and Medicaid.
- Consider the need for guardianship versus powers of attorney for your child.
- Have a school power of attorney form executed and given to the school.
- Obtain an Illinois identification card.
- Check out the RTA reduced fare permit and/or ADA Para Transit Service.
- Males register for Selective Service.
- Register to vote, if applicable.
- Establish a letter of intent and keep it updated.

THE DAY BEFORE YOUR CHILD TURNS 22

Practice due diligence. In Illinois, this is the day school-based services and support end. At least one year before this date, search for and evaluate day and residential programs and community-based services your child may need when school ends.

Little City's Therapeutic Day School



Little City's **ChildBridge
Center for Education**

affords students with autism and other disabilities the opportunity to excel by providing a "bridge" between education and each child's specific developmental disability.

A typical day for each student will include a host of activities outside of the classroom offered throughout Little City's 56-acre, therapeutic campus, as well as a gamut of other leading-edge services.

- Transition Programming
- Art Therapy
- Occupational Therapy
- Speech and Language Therapy
- Social Skills Training
- Community Inclusion and Integration
- 1:1 Instruction
- Computer Resources
- School Health Services
- Sensory Regulation
- And much more!

LEARN MORE
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LITTLE CITY:



ENROLLMENT IS NOW OPEN. CONTACT ADMISSIONS TODAY:
(847) 221-7859 OR **school@littlecity.org**.

littlecity.org/school

Program helps prepare trainees for employment success

Continued from page 6

Through this approach, individuals will have the option to choose a career track in a distribution or retail setting. This program helps prepare trainees for success, not only for potential employment with OfficeMax, but also for potential employment with other businesses within the community.

Kessler Foundation executives say grant monies are used to fund innovative initiatives to help solve the low employment rate for people with disabilities, an often untapped resource in the workforce.

Nationally, OfficeMax trains individuals with significant disabilities in the company's core values, safety skills, job skills and social communication skills. Corporate disability experts from APSE will analyze the activities in each of the four training areas to serve as the foundation for instruction, evaluation and creation of support plans.

Each trainee will have individualized training time,

supports, assistive tools and accommodations to ensure success.

Training people with disabilities for employment is a win-win for both the trainee and businesses, adds Carolyn Brooks, OfficeMax vice president, chief diversity officer.

"Through this partnership, we are creating a diverse and inclusive workplace culture that can attract qualified associates of all abilities and backgrounds to help create innovative business solutions," says Brooks. "We've found that hiring people with disabilities has allowed us to tap into a talented pool of workers that bring unique experiences and understanding that provide OfficeMax with a distinct competitive advantage."

OfficeMax, Aspire, the Illinois Division of Rehabilitation Service and the Rehabilitation Institute of Chicago will create a pre-training model that can be distributed across the company and quickly increase employment opportunities for people with disabilities.

In the two-year grant period, the project will involve at least four OfficeMax facilities and support 40 jobseekers with disabilities. The partnership with Kessler Foundation will enable OfficeMax and APSE to expand the project to other markets across the country.

James Emmet serves as the lead consultant for "Maxing Out Diversity." He was the strategy leader behind the award-winning Walgreens Outreach project that increased recruitment of jobseekers with disabilities.

ABOUT ASPIRE OF ILLINOIS

Through agencies like Aspire of Illinois, businesses can hire capable people with disabilities such as Down syndrome, autism and cerebral palsy. Their community employment services help adults prepare for and find rewarding employment in the community, providing the support each individual needs to find a job that meets individual strengths and interests.

To ensure a smooth transition, the agency provides pre-employment training to help equip adults with important job and workplace skills. Job coaches work right alongside each new employee, helping them to master job skills and succeed.

Aspire of Illinois has successfully worked with leading area employers including Harris Bank, Jewel Food Stores, Mario Tricoci, Portillo's, Sam's Club, TCF Bank, Target, UPS and Walgreens. Through their work together with partners, hundreds of individuals with developmental disabilities have found meaningful work while helping to diversify and humanize the workplace.

Aspire of Illinois provides neighborhood-based services at 21 facilities in West suburban Chicago.

ABOUT KESSLER FOUNDATION

Kessler Foundation, the largest nonprofit organization in the field of disability research and employment, is

a global leader in rehabilitation research that seeks to improve cognition and mobility for people with multiple sclerosis, brain injury, stroke, spinal cord injury and other disabling conditions. It leads the nation in funding innovative programs that expand opportunities for job training and employment for people with disabilities.

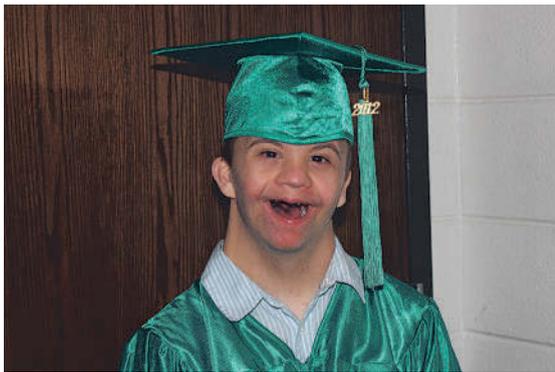
Since 2005, Kessler Foundation has invested more than \$30 million in organizations and programs to increase the participation of people with disabilities, including veterans, in the workforce through strategic funding and philanthropic leadership. For additional information, visit kesslerfoundation.org.

FOR ADDITIONAL INFORMATION

To learn more about autism or for support and resources, contact the Autism Society of Illinois at 2200 S. Main St., Suite 203, Lombard, call (630) 691-1270 or email info@autismillinois.org.

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Little City's ChildBridge Center for Education



The **ChildBridge Center for Education**, *Little City's therapeutic day school*, provides progressive services for students with intellectual and developmental disabilities, as well as, students with severe and profound needs on the autism spectrum.

This day school will "bridge" education and each child's developmental abilities enabling them to reach their fullest potential. A typical day for each student will include a host of activities outside of the classroom offered throughout Little City's 56-acre campus and the surrounding community.

The ChildBridge Center for Education, approved by the Illinois State Board of

Education, collaborates with each child's home school district and develops an Individualized Education Program (IEP) that provides personalized therapies and intervention services to address the student's unique educational needs.

Led by a National Board Certified Teacher, classes in the Center for Education are small with teacher and instructional support staff for elementary, middle and high school. Students are dividing into classes based on their age and student support needs.

Little City provides computer-based training, assistive technology devices and augmentative communication therapies (such as PECS, sign language, AAC devices, etc.). All students have access to iPads within their classrooms that are customized to their learning and communication styles.

The Center for Education provides integrated life skills, academic, clinical and transitional services to help children reach their full potential. Students enjoy art therapy, physical education, assistive and adapted technology, occupational therapy, speech and language therapy, adaptive aquatics and much more.

Students can utilize a unique recreation center that includes a fitness center with

equipment designed for individuals with disabilities, game rooms and a swimming pool with a wheel-chair lift. Also located on-campus is a gymnasium, horticulture center and a gamut of other leading-edge services.

Little City is currently in the process of expanding the Center for Education in order to provide first-rate education programming to more students. The expansion will allow students to transition or travel to and from different classrooms that will focus on specific subject areas.

Students from kindergarten to age 21 are welcomed at the ChildBridge Center for Education.

For more information on the ChildBridge Center for Education, visit littlecity.org/school.

For admissions and referrals contact Admissions at school@littlecity.org or (847) 221-7859.



LANGUAGE DEVELOPMENT

Connectivity-Guided Neurofeedback trains the brain at home

By JANICE YOUNGWITH

HELPING GEORGY

Home may be where the heart is, but it's also now the place families are finding great success in helping their child train the brain to aid in speech/language development, social awareness, attending and much, much more.

With the brain training Connectivity-Guided Neurofeedback experts and technicians headquartered in far west suburban Naperville, families from around the world are excited to begin tapping into their expertise and therapeutic treatment via a customized home-based program and Skype technology.

From bikes and skates to underground train travel, 14-year-old Georgy Burtnik is a teen on the go. But life isn't always easy for Georgy, who lives in Yekaterinburg, Russia — the country's fourth largest city of 1.3 million people. Georgy, who resides in the busy industrial and cultural metropolis with his parents, Vladimir and Natalia, and 9-year-old brother Dimitri, faces a variety of challenges relating to an autism spectrum disorder.

"At age 3, we began seeking a diagnosis due to speech deficits, his behaviors and social skills," recalls his father, Vladimir, 49.



Georgy Burtnik, 14, right, of Yekaterinburg, Russia, benefitted from online sessions of Connectivity-Guided Neurofeedback, which helps those with autism in remapping and rebuilding the brain's neuroconnection. Georgy is pictured with his brother Dimitri, 9.

"Now in his eighth year of an 11-year school program, Georgy requires special care. His teachers not only attend school with Georgy but also come home with him."

The real estate developer says the family's quest to find answers for the debilitating effects of autism was far-reaching and eventually led to

Naperville, where they discovered answers and the promise of a home-based program.

MAKING THE NEUROCONNECTION

"We first learned about a newer type of brain training called Connectivity-Guided Neurofeedback being used to aid those with autism and other neurophysiologic conditions in remapping and rebuilding the brain's neuroconnections online from Ann Rigby at The Neuroconnection in Naperville," recalls Vladimir, who says he was curious to learn more about the promising home-based treatment. "I don't think it is something that is available in Russia."

Vladimir says it was his son's doctor, Dr. Anju Usman of True Health Medical Center, who first mentioned neurofeedback four years ago and who directed the family to The Neuroconnection offices in May 2012. Home-based training began in May 2013. Dr. Usman also recommended attending a conference presentation by Dr. Robert Coben, a neuropsychologist and leading Connectivity-Guided Neurofeedback researcher.

"Dr. Coben and I discussed the possibility of neurofeedback in Russia," recalls Vladimir, who says the discussion led to a better understanding of brain mapping and ultimately to a special facility in the United States, which offered an advanced form of neurofeedback called Connectivity-Guided Neurofeedback based on brain imaging research. Most exciting was news of a protocol for at home therapy — something he could use with his son at home in Russia.

"Neurofeedback training can be very effective with autistic spectrum disorders, particularly Connectivity-Guided Neurofeedback, which trains the way the brain communicates with itself," explains Ann L. Rigby, founder and director of The Neuroconnection, who uses Connectivity-Guided Neurofeedback to help Georgy and other clients form new connections in regions of the brain where they have not been formed previously due to the epigenetic nature of autism.

According to Rigby, the state-of-the-art Connectivity-Guided Neurofeedback has

Continued on page 14

How it works

Based on the latest research, Connectivity-Guided Neurofeedback focuses on brain waves produced by electrical signals as the brain's neurons fire.

"It's a noninvasive, non-medication and painless intervention, which enhances neuro regulation and can improve the ability of the brain to function optimally," says Ann Rigby, founder and director of The Neuroconnection.

Measured using an electroencephalogram amplifier and computer to show when optimum functioning is present, Neurofeedback training sessions induce change by rewarding the brain with sounds and visual images from a movie or game, which is played when the correct brainwaves are produced.

The Connectivity-Guided Neurofeedback process involves the use of specific brain mapping tools that provide three-dimensional statistical computations that show how the brain is communicating with itself. The specific tool that provides a quantitative metric for EEG and measures regions of the brain for connectivity is called NeuroRep, developed by Dr. William Hudspeth.

"These tools take into account the geography and structure of the brain and an understanding of the pathways in the brain that allow information to flow back and forth," explains Rigby, who says it is only with these tools that trained clinicians accurately know where and how to do the correct type of Neurofeedback training.

"Until recent years, the maps that we used only allowed us to look at the brain as if it were flat and did not account for the distance between the sites that we were evaluating," she says. "State-of-the-art brain mapping today enables us to evaluate regions of the brain, looking at areas that are too loosely or too tightly connected and aims to make changes to these abnormalities in functioning."

Home-based component makes training easily accessible

Continued from page 13

proved especially beneficial for those with autism and a new home-based component means the structured therapy sessions easily are accessible to those like Georgy, who live thousands of miles away on the other side of the world.

Because of the brain's lifelong neuroplasticity, the brain can change and form new connections at any age, says Rigby, who currently sees clients ranging in age from 3 to 77. Training takes an average of 60 sessions for moderate autism, and the effects shown in studies over time indicate that improvements are lasting.

The sophisticated Connectivity-Guided Neurofeedback training is particularly effective for clients with autism, she says, as it trains regions of the brain — where neuropathways were supposed to have formed during early development and did not — for better communication and timing.

BRAIN TRAINING AT HOME

Georgy and his family made the trip to Naperville for evaluation, brain mapping, individual protocol development and to learn all they could about running a training session before returning to Russia last summer.

His parents learned in clinic how to use the neurofeedback instrument, loaded with Georgy's protocols, to train Georgy at home. During each home-based 30-minute session, Georgy was connected by two sensors to his scalp and ears and monitored by trained clinicians at The

Neuroconnection via Skype technology. Auditory and visual feedback was provided in the form of a movie of Georgy's choosing.

That same Skype technology also enables other clients from Russia, India and locations across the globe to tap into the highly specialized technology available in suburban Chicago.

"When producing the correct brain waves, the brain seeks out sights and sounds and becomes conditioned to produce correct brain wave patterns more often," explains Rigby, who says "over time, the unconscious process makes changes in brain wave activity and begins producing optimal functioning thus decreasing symptoms."

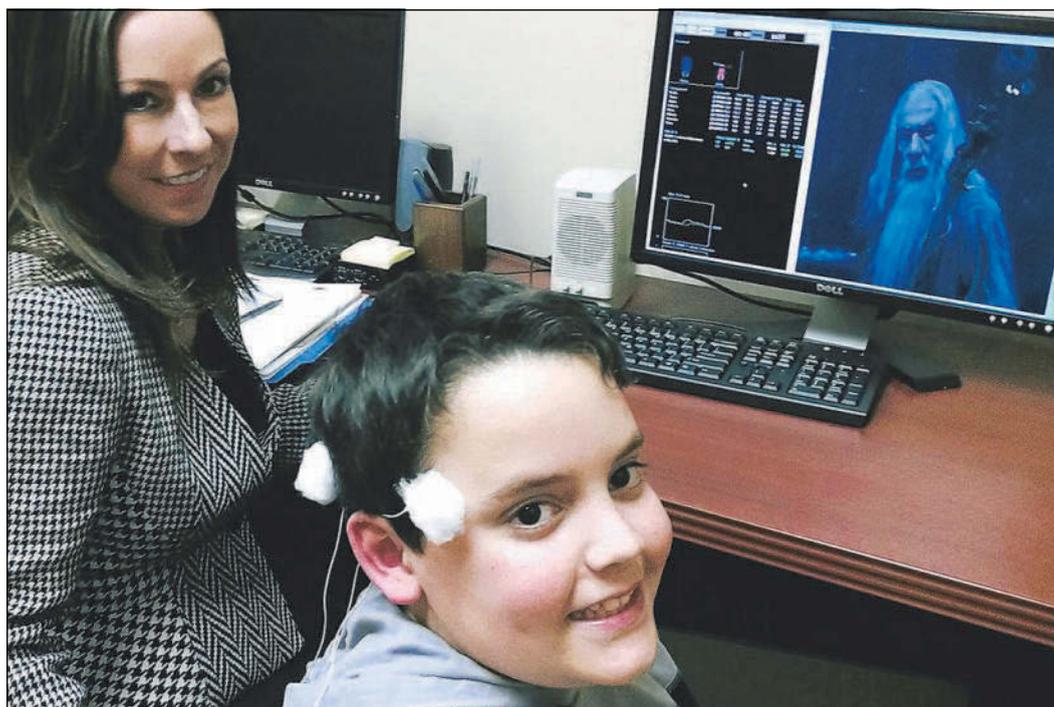
After an initial 20 home training sessions, Georgy's parents reported amazing changes. Their son became more talkative, appeared motivated, paid attention, showed signs of improved memory and his fearfulness decreased.

"We began noticing very positive changes," says Vladimir, who notes the family currently is completing an additional 20 home training sessions.

CODY NIELING'S STORY

Local families, like the Nielings of Wheaton, also are finding success with Connectivity-Guided Neurofeedback available near home. Their 20-year-old son, Cody, recently completed 40 training sessions on the left side of his brain and 20 on the right.

The 2012 Wheaton-Warrenville South graduate who worked as football team



Ann L. Rigby, founder and director of The Neuroconnection, uses Connectivity-Guided Neurofeedback to help Kent Carrasquilla, 9, form new connections in regions of the brain where they have not been formed previously due to the epigenetic nature of autism.

manager for the high school state champion Tigers and who boasts two championship rings, began experiencing increasing levels of panic and anxiety two years ago.

According to his mom, Monica, the issues became so debilitating that her son started to withdraw, was sleeping fitfully, became worried about the end of the world and questioned his own mortality.

"I was so worried and felt he simply couldn't get a grip," says Monica, who recalls her son experiencing lots of personal pressures surrounding testing and grades throughout his school years. "Grades were never really a problem, but he constantly worried about his performance, obsessively checked online grade monitoring sites, tried to do all the extra credit work and worried about being a perfectionist."

While never formally diagnosed, Monica says many of her son's behaviors and challenges seemed to mirror those of Asperger's syndrome. Cody and his family eventually sought help for evaluation, brain mapping and Connectivity-Guided Neurofeedback, turning to Ann Rigby and specialists at the Neuroconnection in Naperville.

"Digital brain mapping showed several areas of serious concern," recalls

Cody's mom. "Some of those areas are typically related to the challenges of attention and attention deficit, something we'd always wondered about."

As training progressed, the Nieling family began noticing gradual changes.

"Cody became more engaged, vocabulary increased, he was happier, started channeling his energy into daily workouts and running and his panic decreased," his mom reports. Twenty-three-year-old sister, Taylor, was shocked upon returning home to Wheaton and receiving a hug from her brother — a tactile sensory input he'd resisted all his life.

"We're still not sure of Cody's future path, but it is definitely promising," notes Monica, who reports her son passed the College of DuPage English placement exam and now has 17 college credits under his belt — along with a 3.0 grade-point average.

KEITH AND KENT CARRASQUILLA'S STORY

The Carrasquilla family of Naperville also says Connectivity-Guided Neurofeedback has played a big role in helping two of their five children: sons Keith, 14; and Kent, 9. According to the

boys' mom, Gretta, it was two years ago when Keith's panic attacks, anger management issues and trouble adjusting came to a head.

While performing adequately in his academics, Gretta recalls her son expressing frustration, anger, obsessive compulsive tendencies, anxiety, trouble sleeping and difficulty focusing.

"He talked about his life not being worth living, and I worried about depression, something which does run in families," says Gretta, who is a clinical dietitian.

Following brain mapping, Gretta says Keith's Connectivity-Guided Neurofeedback sessions focused on the brain's frontal lobe — 20 sessions on the right, followed by another 20 on the left.

"The changes were night and day," she notes. "He's happier, no longer has sleep problems, homework and school work are leading to straight As, and he recently was elected to his Kennedy Junior High leadership group."

Gretta says the family was a little more uncertain about 9-year-old Kent's challenges.

"He had a benign focal seizure of childhood at school, which was reported by his teacher," recalls his mom. "After she noticed

Research basis for Connectivity-Guided Neurofeedback

The research of Robert Coben, Ph.D., a neuropsychologist, is at the heart of Connectivity-Guided Neurofeedback. Dr. Coben reported results of a large-scale 2009 study of 85 children in an experimental group trained using Connectivity-Guided Neurofeedback, which showed a 57 percent decrease in autistic symptoms.

"Using Dr. Coben's model, we have achieved very similar outcomes to his 2009 study that he did, which included a control group," says Ann Rigby of The Neuroconnection in Naperville. "It's not uncommon for our clients to be able to come off stimulant medication, antidepressants and anti-anxiety meds following training."

Kent's chin trembling and his drooling, we followed up with a pediatric neurologist for testing. Seizure control medicine was prescribed."

Throughout kindergarten, first and second grades, Kent lagged behind his peers, couldn't seem to sit still and was easily distracted in the classroom. Teachers reported challenges staying on task, not paying attention, being disruptive and "spacing out."

"They worried that as the academic pace accelerated in third grade, he'd be unable to keep up," says Gretta. "Another medication helped him improve his attention span, and he made a dramatic improvement in school work. But with the medicine only lasting for six hours, we didn't see any of these positive changes at home. I wanted him to be his best at both home and school."

The third grader began with 20 sessions of Connectivity-Guided Neurofeedback on the right side of his brain and currently is completing an additional 20 sessions on the left side, with his parents and teachers now reporting dramatic changes.

"He no longer uses the medication for his attention deficit on weekends, and we hope to wean him off it totally in the near future," reports his mom.

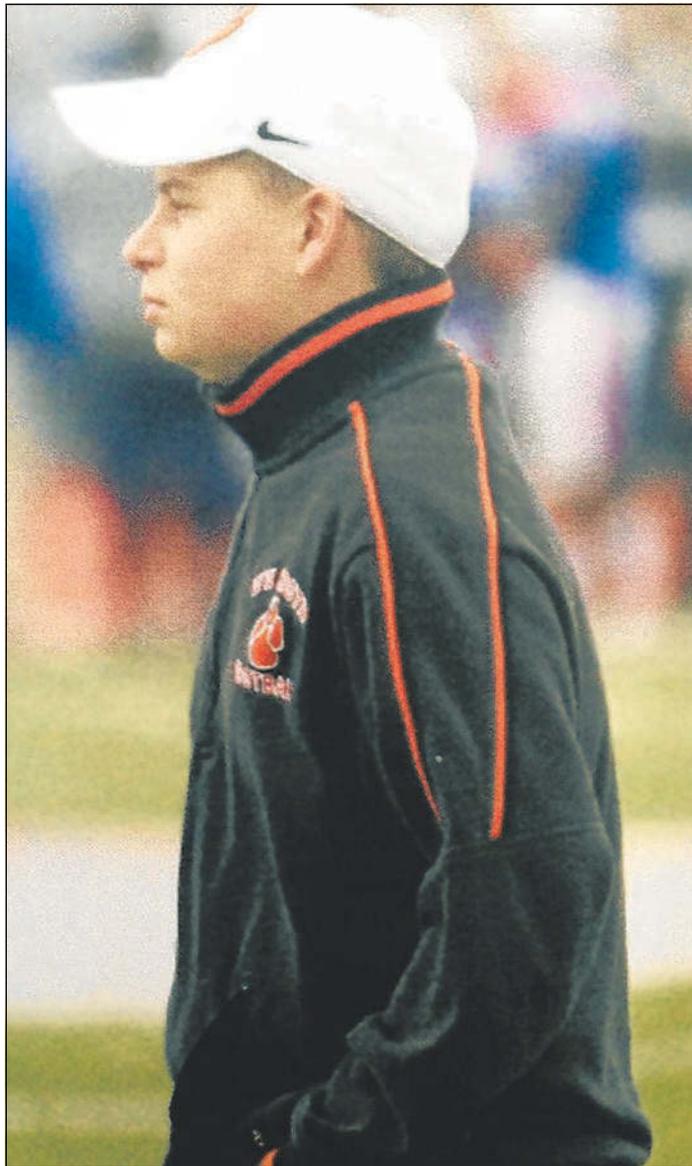
"Kent is now able to sit still and complete his homework, he's more focused and very self-directed. His neurologist will complete another EEG this summer to determine if there has been a change in his need for seizure medication as well."

His mom also notes her son now is more outgoing, has multiple friends and is being invited to birthday parties — something that hadn't happened previously.

"He's brighter, more alert and really a very together kid," she adds.

WHAT THE EXPERTS SAY

According to Rigby, Connectivity-Guided Neurofeedback makes the changes in the brain that allow other therapies to be absorbed faster. The home-based component means therapy is available and accessible to families across the country and around the world.



Cody Nieling, 20, found success with Connectivity-Guided Neurofeedback to help with panic and anxiety issues.

"When you have the neuroconnections that allow you to now perform the tasks, improvements are seen more quickly," says Ribgy, who notes that speech therapy can be enhanced, children are able to pay more attention and get more out of tutoring, become socially aware and engaged and often need to join a social skills group to catch up due to their new awareness and interest in peers.

Among other results is the ability to transition without disruption, increased focus, improvement in social skills and social pragmatics, increased calmness and decreased anxiety, improved verbal communication or expressive language, improved receptive language, fewer repetitive behaviors and improved processing speed.

"The new interest in others, improvement in eye contact and empathy can be an amazing thing to watch," she says.

"A child at the beginning of training, who had no interest in others, will suddenly come into the office engaging with others in the waiting room or carrying on reciprocal conversations with staff when they were not able to do this before."

FOR ADDITIONAL INFORMATION

Neurofeedback has been used for more than 20 years in the treatment of attention deficit, anxiety, chronic fatigue, substance abuse and mood disorders.

It meets the American Academy of Child and Adolescent Psychiatry's clinical guidelines for recommending evidenced-based treatment.

For information on neurofeedback and Connectivity-Guided Neurofeedback, call The Neuroconnection at (630) 858-5105 or visit www.theneuroconnection.com.

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Photo by Jessica Cepete

Marklund Day School teacher Angela and student Nathaniel utilize a SmartTable for a class activity.

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To schedule a tour, contact: Karen Gill, Director of Education
630-307-1882, ext. 3248 or kgill@marklund.org

Marklund
DAY SCHOOL

For information, visit www.Marklund.org/school